


Digital Vision for Personalised Care for People with learning disabilities




Contents

- Recommendations
- Project Background and context
- Objectives
- Methodology
- Key insights
- Conclusion






“This work explores how digital services can adapt to face the challenge of accessibility whilst understanding that for some the ‘digital first’ option will lead to further marginalisation and the risk of crisis situations.”






Recommendations: Making Digital Work

- For people with learning disabilities services **must never be digital by default**. This should only be an option where appropriate.
 - People on the learning disability register who wish to opt in must be **offered ongoing support with the service**. (Tech support/trouble shooting helpline)
 - Ongoing **monitoring** must be carried out to **identify unforeseen problem** areas. (Problems may only be noticed when something has gone wrong, which may have serious implications for some people)
 - Work developing these tools needs to be done in accordance with the **Accessible Information Standard**
 - **User testing** to be carried out with young people who are moving towards a more independent life.
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Recommendations: Next Steps

- Contact special schools and colleges
 - Understand the websites and apps education and parents use. Using similar systems to those people are already familiar with reduces time learning how to use new systems.
 - Understanding IT digital courses colleges provide for learning disabled people
 - Consultation with support providers
 - Look into support workers/providers experience and barriers to helping someone manage their health
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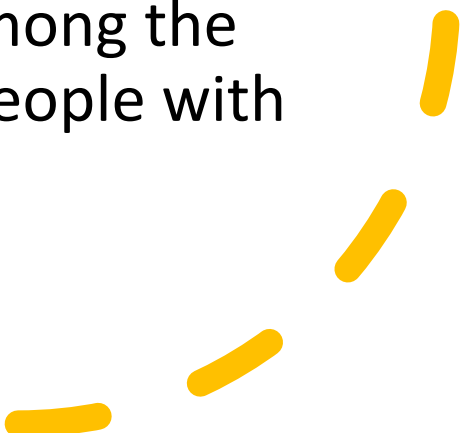


Background

Health and social care services in primary and secondary care are increasing using online or digitized systems to provide some or all of their services to their patients (clients or service users).

For some people this can be a fast and effective way of accessing services and information.

However, there is increasing recognition that 'digital exclusion' is most common among the elderly, those on a low income and people with learning disabilities.




What is personalised care?

Personalised care is one of the five major, **practical changes** to the NHS set out in the Long Term Plan.

Personalised care means people have **choice and control** over the way their **care is planned and delivered**. It is based on 'what matters' to them and their **individual strengths and needs**.

This happens within a system that makes the most of the **expertise, capacity and potential** of people, families and communities in delivering **better outcomes and experiences**.

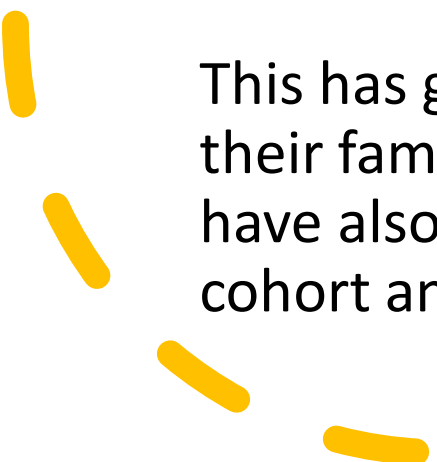




Context of this project

This project was meant to be carried out in person with face to face interviews and focus groups. Due to coronavirus that has not been possible.

This has given us a unique opportunity to talk to people over a period where digital services have been essentially all that's available.



This has given us insight into the barriers that people with learning disabilities and their families face in a society where services are becoming digital by default. We have also been able to observe the positive aspects of digital connection for our cohort and identify what systems are most accessible to them.

Project Objectives

The objective of this project was to ensure the Personalised Care Group have information to ensure that digital tools and solutions for personalised care are inclusive and meet the accessibility requirements of people with learning disabilities.

The aims of this project were to begin to:

- Identify the ways in which some people with learning disabilities (and their families) already use digital platforms and access digital info
- Identify ways that people can increase their use of digital tools
- Identify what demographics are most likely to use digital tools
- What demographics are likely to be the most excluded and why
- Identify skills needed and barriers to accessing digital media
- Identify system issues needing consideration to remove barriers

Methodology

The consultation for this project was completed by Brighton and Hove Speak Up and Oxfordshire Family Support Network (OXFSN) during April and May 2020.

Brighton and Hove Speak Up

24 learning disabled people took part in individual interviews and focus groups.

All participants were local and between the ages of 16 and 85.

Most lived with family (6), in residential care (5) or in sheltered accommodation (5). See appendix 1 for full break down.

Oxfordshire Family Support Network (OXFSN).

10 family carers, including one sibling, of people with learning disabilities

Each family carer completed an hour long phone interview, responding to 10 questions.

Family carers were aged between 18 and 80 years old. Their learning disabled children were aged between 8-54. 7 lived at home, 4 in supported living and 1 in an ATU.

Who manages people's health care?

- In the majority of cases personalised care is currently managed by families and those who support people with learning disabilities.
- People who **live independently**, are more likely to manage their own health care and be more independent in using technology. However the support this group receives is often not responsive to their health, particularly in emergencies. Additionally, low levels of support mean people are more at risk of digital exclusion.
- People who **live at home** typically have their health care managed by their family.
- People who **live within a service** are mostly supported by care staff to manage their health care. This can sometimes be a manager, key worker or a range of support workers and often depends on the setting. We didn't talk to staff as part of the project. People told us the success of this is dependent on the time, skills and willingness of staff. Families often continue to play a role.

Experiences of managing health care

Families

Families work very hard to establish their current arrangements, managing relationships as well as large volumes of information and records.

Knowledge of their child and complex systems often comes from peer support and is supplemented by online information.

They often cite relief at handing over the responsibility to the care providers to deal with. This was cited by all family carers indicating what a **worry and burden** managing health care is for family carers.

*“It’s a **relief** that someone else is taking **responsibility**.”*

People with learning disabilities

Managing health care can be **daunting and complex** task.

This largely means people rely on others to manage their health care for them.

People have worked very hard to establish arrangements that work for them. Yet these managing health care remains difficult and often excludes the learning disabled person. Digital services must make the experience easier.

What do people with learning disabilities do online?

Who?

- Those who use digital platforms are typically people with the highest levels of independence.
- The majority of them are aged under 40

What do people use it for?

- Devices are often used for games, entertainment, shopping and information gathering.
- Whilst most people had an email address this was often managed for them, as were passwords.
- Largely people do not manage finance, health or social care digitally.
- People can be creative in using assistive technology to help them use the internet more independently

Ownership

The most used device is a smart phone.

Barriers

- Internet access and owning technology is expensive
 - Many people therefore don't have access
 - Or access is managed or restricted by someone else
- Many people lack ICT and literacy skills
- Websites and apps aren't accessible
- Lack of support to access ICT or manage own health
- Fear of being hacked or scammed

What do families do online?

Ownership

All the families had a mobile phone and landline. Most owned a tablet but laptop or PC ownership was minimal.

Competency and confidence

ICT skills and confidence varied, typically by age. Despite younger people having higher confidence and competency levels preference for phone calls remained.

Age Group	Described Competency
70-80	<ul style="list-style-type: none">• Did not use any websites, or apps• Relying solely on GP consultations for medical information and interpretation of hospital letters
30-50	<ul style="list-style-type: none">• Confident using websites and apps- reflecting their social media use.• Minimal to no use of apps for medical information. Relying on medical and social care professionals for advice, information and interventions• Concerns focused on the quality and accuracy of the information and the skills needed to get the information needed.
18-30	<ul style="list-style-type: none">• Confident using websites and apps. Reported use of some online medical services from GPs and Dentists.• Remaining preference for phone over online services

Digital Exclusion

- People and families are excluded for a number of key reasons:
 - They lack skills and confidence
 - They aren't supported to access digital services
 - They don't have the technology
 - Their access to technology is managed by gatekeepers
- This largely affects disabled people who don't have lots of support, people who live within support providers settings, and those on low incomes.
- In terms of families this largely impacts older people and those with low incomes.

Making the call

Face to face or phone contact is the preference currently for almost everybody when managing medical appointments. This is the case for all family carers regardless of ICT competency and confidence.

The **Key Reasoning** for working this way are clear to those managing personalised care:

- The advantages to using online systems were not clear to people whereas the barriers were
- Phoning is simpler and saves time as it reduces the number of steps to achieve the desired outcome
- Online systems aren't designed for the complexities of peoples reasonable adjustments or personal histories
- Families have spent time developing relationships with professionals to try ensure they get a good quality service.

It is important to remember this isn't always accessible either.

'My mum helps me ring up. If they are not helpful I get her to talk to them.'

People often need to negotiate to get their desired outcome, therefore a phone call is seen as more productive.






Key Insights: Potential of online services

For learning disabled people digital services could address many of the issues that are important to them.

- Giving people choice and ownership over their health care
- Have their learning disability and reasonable adjustments flagged
- Receive health information in accessible formats
- Recognize their statutory rights to an Annual Health Check, Health Action Plan and longer appointments



Younger family carers could see some advantages to online services.

- For those who are safer or more comfortable at home the experience could be quicker, less stressful, save travel time and parking.
 - Digital services increase the ability for services to share and centrally store information, reducing the need for people and families to repeat their histories to get services that will work effectively.
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Key Insights: Choice and voice

- Concern for online impacting the quality of interactions leading to clinical decisions being based on poor information.
- There is worry the people's presence and voice would be lost through online consultation, having to heavily rely on family carer to interpret and translate for them




Potential

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- Accessible websites and services make it possible to included learning disabled people in their understanding and planning their own health. This contributes to a feeling of ownership that makes people more engaged with their health and wellbeing.

Key Insights: Relationships

The relationship with the medical professional was extremely important for the learning disabled person and family carers. Many families had spent years building relationship to improve their experiences using services.

- There was worry through increased digital care the relationship between the medical professional and their patient would be eroded and be dehumanizing for both parties.
- Families worried the quality of the interaction with the medical professional could be reduced by the technology itself – e.g unstable connection leading to poorer decision making

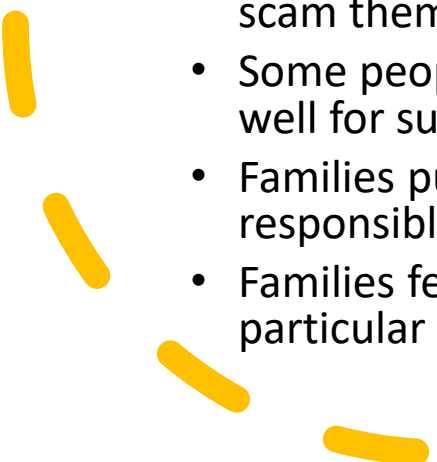


Key Insights: Security, confidentiality and privacy

- **Passwords**

- Most learning disabled people find using and managing passwords difficult to impossible.
- For families multiple log-ins, collecting passwords in person, partial access and inaccurate information put them off online services instantly. Many are concerned they aren't managing passwords securely.
- They don't know how support providers are storing passwords and this causes worry.

- **Confidentiality and Privacy**

- Learning disabled people were often worried about people using their information to take advantage, scam them or steal their identity.
 - Some people who's care is managed by support workers sometimes had to ask people they didn't know well for support. Leaving them open to abuse.
 - Families put a great deal of trust in medical and social care professionals to manage information responsibly. However, lack understanding of how this information will be stored.
 - Families felt frustrated by digitization information sharing protocols between health and social care in particular meant information could not be shared. This caused a great deal of frustration and confusion.
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Key Insight: Access




Both Learning Disabled people and families are clear that inaccessible websites and apps are a significant barrier to accessing digital media and services.

While younger people are typically 'digital natives', people from all age groups with a learning disability who used some technology could adapt it to meet their needs.

'I've got an iPhone. If my mum texts me I get Siri to read it. If I get a letter through the door and no one can help me read it I take a picture and send the photo on WhatsApp. I use WhatsApp and Facetime.'



Despite their creativity people still could not navigate services, online forms or written information.



Providing services that meet accessibility standards helps people with learning disabilities, their families but also other disabled people, elderly people and those who speak English as a second language.

What do accessible digital services look like?

People like	People struggle with
Film: deliver information by film not text	Online forms, written information, passwords, user IDs
Images: plenty of photographs to support text	People find 'signing in' difficult
Large and audio described buttons	Large amounts of text
Contrast button to change background or text colour	Use of Jargon
People currently use YouTube, Snapchat, WhatsApp, Facebook, Vimeo, Instagram And have an understanding of how to navigate them	

These websites are currently used: NHS Health A-Z , WikiMe, MyGOSH and EasyHealth



Key Insight: Skills and Knowledge

People with a learning disability are open and willing to learn to use online services.

They want to learn in ways they choose, that suit them.




People want to build on the skills they already have, around using social media and entertainment apps.

It has also been reported (Health Information Online for People with a Learning Disability, Change 2016) that degree of literacy was not found to be correlated with use of computers. This means those with lower literacy skills could still benefit from online services with the right support and training.

Giving young people training as part of their EHCP would be a good step in helping them prepare for more independent futures.



Families have to see why the new digital service or website offers good or better care than what they have worked extremely hard to get in place.



Families were open to Websites and Apps which received positive reviews and were complex to use, (e.g. WikiMe requires a training course) but family carers were willing to do it because it met their family members' needs. While these complex systems meet parents needs they continue to exclude learning disabled people.

Conclusion

Overwhelmingly, learning disabled people and their families prefer face to face contact when managing their personalised care. Having said this, they are open to the potential opportunities of opt-in digital services.

They are clear that for digital services to be properly utilised, its use needs to provide a clear advantage in comparison to what they currently are doing. Although current situations are often burdensome, families have fought hard to get them in place. Digital services must make life easier rather than be an additional barrier to personalised care.

Being opt-in is essential as for some people and families accessing online services is impossible, not desirable or due to minimal support, potentially harmful.

For digital services to work barriers must be overcome around

- Designing services to prioritise people's ownership of their own health
- Making all services accessible and flexible
- Training and support must be available
- Security and privacy must be addressed